
March 31, 2021

Marissa Gordon-Nguyen
Senior Advisor for HIPAA Policy
Office for Civil Rights
U.S. Department of Health and Human Services
200 Independence Avenue SW
Washington, DC 20201

Attention: Proposed Modifications to the HIPAA Privacy Rule to Support, and Remove Barriers to, Coordinated Care and Individual Engagement NPRM, RIN 0945-AA00

Dear Ms. Gordon-Nguyen:

The Western Governors' Association (WGA) submits the following comments to the U.S. Department of Health and Human Services' (HHS) Office for Civil Rights (OCR) on the proposed changes detailed in its notice, Proposed Modifications to the HIPAA Privacy Rule to Support, and Remove Barriers to, Coordinated Care and Individual Engagement (86 FR 6446). WGA represents the Governors of the 22 westernmost states and territories and is an instrument of the Governors for bipartisan policy development, information-sharing and collective action on issues of critical importance to the western United States.

The proposed modifications would affect protected health information (PHI) and increase permissible disclosures of PHI to improve care coordination and case management. In WGA Policy Resolution 2020-05, *Physical and Behavioral Health Care in Western States* (attached), Western Governors discuss the importance of access to care and ensuring that health records are accessible to relevant health care providers while maintaining adequate protections for patients. The Proposed Rule's intent to expand provider access to needed PHI for patients and to empower patients with their data is consistent with Western Governors' policy.

In WGA Policy Resolution 2021-02, *Utilizing State Data in Federal Decision Making* (attached), Western Governors urge the Executive Branch to develop uniform privacy and data stewardship policies that adequately protect personal and confidential information. The Governors note that federal agencies should work with state and local partners to develop these standards based on best practices for data stewardship.

The proposed changes encourage data sharing for integrated, whole-of-person health care. They also provide an opportunity to promote data uniformity standards and data infrastructure modernization, which would improve response to health emergencies like the COVID-19 pandemic.

However, patient data privacy concerns must be considered in this rulemaking as well. The proposed rule allows patients to direct their PHI to a third party but does not consider the privacy ramifications for personal and confidential information once it leaves a HIPAA-covered entity, nor does it consider the effect of state privacy laws on third party entities that may receive PHI from a covered entity. The safety and security of personal data is of the utmost importance to Western Governors, and we encourage HHS to consider additional rulemakings to address this issue.

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Western Governors reiterate the need to extend improvements in care coordination to all patients, specifically those with substance use disorders (SUD), by continuing to align federal privacy requirements for SUD (42 CFR Part 2) with the requirements for all other medical conditions under HIPAA. The Governors support the efforts that have already been made but recognize the need for additional federal action on this matter.

While we generally support these changes, they are not without cost to state Medicaid programs in addition to other payers. In light of these potential impacts, we urge the OCR to work with the Centers for Medicare and Medicaid Services (CMS), the Center for Consumer Information and Insurance Oversight (CCIIO), and other HHS entities to coordinate proactively with state Medicaid agencies and insurance commissioners to achieve the intended policy outcomes with minimal disruption to payers.

Western Governors submit these remarks through the public notice and comment process for administrative recordkeeping purposes, although the Governors maintain that this process is an insufficient channel for state-federal communication on federal actions that may affect state authority or administrative activity. Western Governors implore you to engage in early, meaningful, substantive and ongoing consultation with states in advance of any such decisions or related public processes moving forward. Consultation will result in more effective, efficient, and resilient federal policy, benefiting our shared constituents.

Thank you for your attention to this matter. Please let us know how Western Governors may be of assistance in this effort.

Sincerely,



Kate Brown
Governor of Oregon
Chair, WGA



Brad Little
Governor of Idaho
Vice Chair, WGA

Attachments



Policy Resolution 2020-05

Physical and Behavioral Health Care in Western States

A. **BACKGROUND**

1. Ensuring access to high-quality, affordable health care is critical to maintaining and enhancing the quality of life in western states for our growing populations and is the foundation of building and maintaining healthy communities and healthy economies.
2. Western states face unique challenges in health care, including growing rates of substance use disorder, provider shortages in underserved and rural areas, and limited access to broadband. Low population densities and the vast distances between population centers also make it difficult for providers to establish economically-sustainable health care practices in rural areas.
3. Distance and density also inhibit construction of the technology infrastructure that would provide or improve broadband connectivity in underserved and rural areas. Expanding broadband access provides numerous quality-of-life benefits for rural Americans, including economic development, social connectivity, education, public safety, and access to telehealth and telemedicine.
4. The health care sector faces severe personnel shortages in western states, despite efforts of Western Governors, such as the foundation of Western Governors University and other medical training programs in western states, to ensure adequate numbers of qualified medical personnel. This challenge is particularly acute in the West's underserved and rural areas. Ensuring access to health care services requires an adequate number and distribution of physicians, nurses, counselors and other trained health care professionals. Population growth, aging residents, and challenges involving Tribal health care and services for veterans require a renewed focus on developing our nation's health care workforce.
5. In many cases, health disparities and barriers to accessing health care are particularly acute for certain populations in the West. Understanding the impact of social determinants of health (SDOH) on health and health care can inform the development of effective policy to increase access and improve health outcomes for these populations. The U.S. Department of Health and Human Services (HHS) defines SDOH as conditions in the environments in which people live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks. It has also identified five key areas of SDOH: economic stability; education; social and community context; health and health care; and neighborhood and built environment.
6. Western states have a unique body of experience, knowledge and perspective with respect to health care. The Western Governors' Association (WGA) is ideally situated to collect and disseminate information, including best practices, case studies and policy options, that states can use to improve the foundation for health care services and advocate for shared policy priorities on behalf of their citizens.

Behavioral Health Considerations

7. Behavioral health needs are often associated with negative stigma and harmful misperceptions, which can have many detrimental effects, including: a lack of understanding by family members, friends, co-workers and others; reduced professional, educational and personal opportunities; various forms of discrimination; and bullying, physical violence or harassment. Stigma can result in a reluctance to seek help or treatment, and contribute to self-doubt and shame associated with behavioral health conditions and substance use disorders.
8. Western states struggle with access to behavioral health services and higher-than average suicide rates. The ten states with the highest suicide rates in the nation are all located in the West.
9. Integrating behavioral and physical health care services can have many positive effects on health outcomes and health care spending. Behavioral health integration presents a more holistic approach to patient care, offers increased convenience and access for consumers, and can produce significant cost savings for the health care system. Integration can also be an effective tool to de-stigmatize treatment for behavioral health and substance use disorders.
10. Substance use disorder (SUD), including alcohol and drug misuse, is a major public health and safety crisis affecting nearly 21 million Americans. It is particularly prevalent in western states where individuals are more likely to experience or have a family member with SUD. SUD crosses all social and economic lines and tragically takes the lives of tens of thousands of Americans every year. Much attention has been focused on opioid use, and recent federal investment has prioritized opioid prevention and treatment. In western states, however, methamphetamine overdose deaths outpace those resulting from opioid use. It is important to recognize that SUD encompasses all drug classes and to balance SUD investment accordingly. While state and federal progress has been made to address SUD, additional efforts are necessary to help bridge prevention, treatment and recovery gaps in western states.
11. Jails and prisons have become de facto behavioral health treatment facilities. This reality results in inefficient use of public resources and poor outcomes for patients. Youth experiencing a first episode of psychosis are too often sent to juvenile halls, and adults with mental illness and SUD become incarcerated without proper treatment for their underlying chronic behavioral health conditions.
12. Many people experiencing homelessness also struggle with a behavioral health condition. Both supportive housing and adequate, coordinated health and social services must be available to prevent and reduce homelessness for people with mental health and substance use disorders.
13. The quality and completeness of patient records is an important element of care coordination and patient safety. Ensuring the protection and privacy of these records is a critical aspect of maintaining patient confidence in the health care system and ensuring that patients are forthcoming about their behavioral health needs.
14. Currently, federal privacy rules prohibit substance use disorder treatment providers from fully participating in health information exchanges. This may leave health care providers without a full understanding of a patient's medical history and use of medications, which can reduce the quality of care and lead to negative patient outcomes, including potentially deadly medication interactions.

15. Electronic health records (EHR) and state Prescription Drug Monitoring Programs (PDMP) are important tools in addressing the opioid crisis, allowing prescribers and pharmacies to help prevent opioid misuse. At present, there are instances of limited interoperability between EHRs and PDMPs that reduce the potential positive effect of these tools on patient safety.
16. Current federal statute limits the ability of state Medicaid programs to cover inpatient and residential treatment and recovery services at facilities with more than 16 beds, also known as the Institutions for Mental Diseases (IMD) exclusion. This antiquated limitation prevents many adults with behavioral health needs from receiving adequate treatment in a licensed health care facility. Waivers for this exclusion offered by the U.S. Department of Health and Human Services (HHS) have provided states with important flexibility and improved access to treatment for patients with SUD, but barriers still remain.
17. Medication-assisted treatment (MAT), including opioid treatment programs, combines behavioral treatment and recovery services with medications to treat substance use disorders. While MAT has been proven to improve health outcomes and reduce mortality among opioid addiction patients, stigma and myths surrounding the use of MAT limit its potential use in SUD treatment and recovery.
18. The passage of the SUPPORT for Patients and Communities Act in 2018 was a significant step forward for MAT, including by promoting greater flexibility in the use of MAT and expanding access to and coverage for MAT. However, significant limits remain on MAT use and providers' ability to take full advantage of these treatment methods.
19. Support from individuals with lived experience, peer support groups and community-based organizations, including faith-based and cultural organizations, is an important component of effective treatment and recovery for SUD and other behavioral health conditions.

B. GOVERNORS' POLICY STATEMENT

1. Federal efforts to address health care workforce and access needs should reflect early, meaningful and substantive input from Governors, who are best positioned to assess the needs of their states and help develop solutions to meet these needs. State-federal collaboration and coordination are integral to addressing these health care challenges. Wherever possible, and where appropriate, the federal government should respect state authority and maximize flexibility granted to states and Governors.
2. The federal government should work with states to facilitate the deployment of broadband to underserved and rural areas, recognizing that adequate broadband access has a direct correlation to rural populations' ability to access telehealth and telemedicine.
3. Despite efforts by Western Governors to address the shortage of qualified health care workers, significant challenges remain. Governors urge the federal government to examine and implement programs to ensure states have an adequate health care workforce – including in primary care, behavioral and oral health as well as other in-demand specialties – that is prepared to serve diverse populations in urban, suburban, and rural communities. Understanding that there remain significant disparities in access and treatment for many populations, Governors also support efforts to increase the diversity of the health care workforce to improve health outcomes for all.

4. Western Governors recognize the role that social determinants of health (SDOH) have on the health outcomes and well-being of our citizens, and the effect that social determinants – including economic stability, education, social and community context, and neighborhood and built environment – have on an individual’s health status. Western Governors support efforts to identify risks facing high utilizers of health care services including food insecurity, domestic violence risk, unmet transportation needs, housing, utility and other essential supports and services, and to develop innovative models designed to improve coordination of medical and non-medical services and use of evidence-based interventions. These models can provide valuable information on how meeting non-health needs and addressing other social determinants can improve overall health status and decrease health spending.
5. Western Governors encourage Congress to adopt legislation that would empower states and local governments to address persistent economic and social conditions – like limited access to health care providers, stable housing, reliable transportation, healthy foods, and high-quality education – that often hinder health outcomes. Such legislation would assist states in developing plans to target social determinants that negatively affect health outcomes for western populations.

Behavioral Health Policy

6. Western Governors believe patients should have the same access to behavioral health care as they have for physical health care.
7. Western Governors support efforts to improve the quality and quantity of behavioral health services available to our residents, as these services are essential to reducing suicide rates and treating a range of behavioral health conditions, including substance use disorder.
8. Western Governors recognize and support efforts at the federal, state and local levels to promote the integration of physical and behavioral health services. The Governors encourage Congress to adopt legislation and the Administration to implement policies that support states’ integration efforts and that encourage health care providers to better integrate behavioral and physical medicine into their practice of care.
9. Western Governors believe the federal government should work toward treating addiction as a chronic illness and work with Western Governors to develop strategies for addressing substance use disorder that work in concert with state efforts and recognize regional variations in substance use disorder patterns.
10. Western Governors believe that the federal government should take steps to increase opportunities for early intervention and law enforcement diversion to prevent entry into the justice system for individuals with behavioral health conditions. That includes providing law enforcement and emergency service providers with the resources and training they need to divert when appropriate, and expanding the availability of community reentry programs that provide appropriate treatment for underlying behavioral health conditions that contribute to involvement in the justice system.
11. Western Governors support efforts to increase the availability of transitional and permanent supportive housing with coordinated health and social services to more fully support and sustain recovery for people with behavioral health conditions.

12. Western Governors encourage Congress to pass legislation that aligns federal privacy requirements for substance use disorders (42 CFR Part 2) with the requirements for all other types of medical conditions under the Health Insurance Portability and Accountability Act (HIPAA) to improve care coordination and reduce stigma for patients with SUD.
13. Western Governors believe the federal government should take steps to support and help sustain states' administration of PDMPs and ensure that EHRs and PDMPs are fully interoperable between states and the federal government, accessible to relevant health care providers, including opioid treatment providers, and include adequate protections for patients from stigmatization and discrimination.
14. Western Governors support legislation to address the so-called Institutions for Mental Diseases (IMD) exclusion to improve access to SUD treatment and recovery services at residential and inpatient facilities with more than 16 beds, as well as to the full continuum of community-based behavioral health care. This policy solution must also improve access to both inpatient and ongoing, recovery-focused treatment in community settings. Until a legislative solution is enacted, the federal government should continue working with states to provide IMD waivers that offer important flexibility and improve access to treatment for patients with SUD. Implementation of these waivers must also occur in connection with expansions of the full community-based continuum of behavioral health care so that consumers receive services in the lowest level of clinically appropriate care in the community whenever possible.
15. Western Governors support legislative action to increase access to MAT for patients with substance use disorder. This includes eliminating the unnecessary and burdensome registration requirements for physicians, physician assistants, and nurse practitioners to obtain a waiver from the Drug Enforcement Administration to treat opioid use disorder with buprenorphine, which would provide health care professionals with additional flexibility to use MAT to treat opioid-related SUD.
16. Western Governors urge the federal government to develop an evidence-based national education and awareness campaign to reduce the stigma associated with mental health and substance use disorders and encourage individuals to seek help for these health conditions.

C. GOVERNORS' MANAGEMENT DIRECTIVE

1. The Governors direct WGA staff to work with Congressional committees of jurisdiction, the Executive Branch, and other entities, where appropriate, to achieve the objectives of this resolution.
2. Furthermore, the Governors direct WGA staff to consult with the Staff Advisory Council regarding its efforts to realize the objectives of this resolution and to keep the Governors apprised of its progress in this regard.

Western Governors enact new policy resolutions and amend existing resolutions on a bi-annual basis. Please consult westgov.org/resolutions for the most current copy of a resolution and a list of all current WGA policy resolutions.



Policy Resolution 2021-02

Utilizing State Data in Federal Decision Making

A. **BACKGROUND**

1. State and federal agencies increasingly rely on quantitative and qualitative data to inform evidence-based policymaking, improve service delivery, more effectively manage resources, improve regulatory enforcement, and more accurately measure program performance and effectiveness.
2. States serve a critical function as a primary sources and stewards of economic, social, geospatial, scientific, technical, and other datasets that support a wide array of federal agencies and programs. State agencies often have the best available science, expertise, and other institutional data resources for purposes of federal decision-making processes.
3. States are both sovereignties and the primary administrators of numerous federal administrative and regulatory programs under a system of cooperative federalism, which distinguishes them from other non-federal sources of data.
4. State agencies also rely on timely access to current and accurate federal datasets to inform their own decision-making processes, develop more effective policy, improve service delivery and public communication, and to administer federally-delegated administrative programs.
5. In addition to federal laws and regulations, state agencies operate under their own privacy and data stewardship laws, regulations, and policies that protect personal and confidential information from public disclosure or other inappropriate use or disclosure. These protections help establish public trust that ultimately improves government effectiveness.
6. Public access to datasets that serve as the basis for federal agency actions promotes transparency and accountability in the decision-making process. Nevertheless, blanket requirements to make publicly available all data considered by federal agencies – particularly if this data consists of raw data provided by states – may infringe upon states' statutory imperatives to protect personally identifiable and otherwise sensitive information. It may also infringe upon fundamental privacy and data stewardship principles like purpose specification and data minimization. Even where there is no state legal barrier to disclosure of raw data, state agencies may maintain significant reservations about the public release of raw data.
7. The 2019 Federal Data Strategy directs federal agencies to “[e]ffectively, routinely, transparently, and appropriately use data in policy, planning, and operations to guide decision-making [and] share the data and analyses behind those decisions.” Additionally, agencies are directed to “[f]acilitate data sharing between state, local, and tribal governments and the Federal Government, where relevant and appropriate and with

proper protections, particularly for programs that are federally funded and locally administered, to enable richer analyses for more informed decision-making.”

8. Improvements in intergovernmental data sharing, stewardship, integration, protection, and utilization will require robust federal investments in a modern data infrastructure, technology, and training.

B. GOVERNORS' POLICY STATEMENT

1. State data serves a critical role in the successful implementation of a variety of federal programs and in federal agencies' fulfillment of their statutory missions and directives.
2. Subject to state laws and other requirements for data protection and transparency, federal agencies should be required to incorporate state and local data and expertise into their analysis and decision-making processes. This data should include geospatial, scientific, technical, economic, social, and other information relevant to issues the agency is trying to address.
3. Congress and the Executive Branch should look to states and state agencies as partners – rather than ordinary stakeholders – in the collection, stewardship, analysis, and use of data to inform federal decision-making processes. Federal agencies should recognize the existence and limitations of state privacy and data stewardship laws, regulations, and policies and work with states to develop strategies that encourage effective state-federal data sharing while appropriately protecting data according to state law.
4. State data – particularly non-aggregated raw data – is subject to differing levels of protection under various state laws, regulations, and policies. Western Governors encourage Congress and federal agencies to recognize the limitations on complete transparency of state data in federal decision making and to work with states to identify ways in which protected data can inform federal decision-making processes without conflicting with applicable state laws, regulations, or policies.
5. Federal agencies should consult with states – on a government-to-government basis – in the development and implementation of policies, programs, and strategies to more effectively and consistently incorporate state data into federal decision making, including implementation of applicable federal statutes and programs, as well as the Federal Data Strategy and development of annual Federal Data Strategy Action Plans.
6. Federal agencies should also consult with states to ensure that state and local partners have access to timely and reliable federal datasets for purposes of informing state and local decision-making processes.
7. Congress and the Executive Branch should support, and work with state toward, the modernization of our nation's data infrastructure and intergovernmental data-sharing and analysis capabilities. Data infrastructure should be based on best practices for data stewardship and must properly protect personal and confidential information in accordance with state and federal law. Federal agencies should consult with states to develop guidelines for intergovernmental data-sharing agreements and other protocols that include commitments to fundamental privacy and data stewardship principles like purpose specification and data minimization.

8. Federal agencies should work with state and local partners to develop uniform data standards, where appropriate, to maximize data quality and facilitate intergovernmental data use, access, sharing, and interoperability.
9. Western Governors support congressional efforts to broaden statutory exemptions under the Freedom of Information Act to protect personally identifiable and sensitive state-shared data from disclosure.
10. Western Governors urge the Executive Branch to develop uniform privacy and data stewardship policies based on best practices and uniform interpretations of federal privacy and data stewardship laws, regulations, policies, and other directives applicable to data received from states, as well as other non-federal sources.

C. GOVERNORS' MANAGEMENT DIRECTIVE

1. The Governors direct WGA staff to work with congressional committees of jurisdiction, the Executive Branch, and other entities, where appropriate, to achieve the objectives of this resolution.
2. Furthermore, the Governors direct WGA staff to consult with the Staff Advisory Council regarding its efforts to realize the objectives of this resolution and to keep the Governors apprised of its progress in this regard.

This resolution will expire in December 2023. Western Governors enact new policy resolutions and amend existing resolutions on a semiannual basis. Please consult <http://www.westgov.org/resolutions> for the most current copy of a resolution and a list of all current WGA policy resolutions.